

BMJ Open Carer strain in post-stroke emotionalism: a cross-sectional analysis

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ABSTRACT

Objectives Post-stroke emotionalism (PSE) is a common, under-researched neurologic symptom of stroke, characterised by frequent crying episodes not under usual social control. Currently, there are no data on carer strain in the context of emotionalism after stroke. We aimed to explore the degree of carer strain in carers of individuals with diagnosed PSE compared with carers of individuals with stroke but no PSE to examine whether carer strain varies with particular characteristics of the cared for individual (patient age, sex, social deprivation, stroke type, functional status, mood status) and to quantify the impact of PSE on carer strain, after accounting for other factors.

Design Cross-sectional observation study.

Setting Nine secondary care stroke units in Scotland, UK.

Participants 102 informants of people with stroke.

Primary and secondary outcome measures The Modified Carer Strain Index was completed at 6 months post-stroke as part of the Testing Emotionalism After Recent Stroke (TEARS) longitudinal cohort study between 1 October 2015 and 30 September 2018. Stroke survivor diagnostic status was determined using TEARS-Diagnostic Interview based on published, widely accepted diagnostic criteria of emotionalism.

Results There was little evidence of association between carer strain and sex, age, deprivation level or stroke type of the cared for individual. There was strong evidence that carer strain was associated with both increased functional dependence post-stroke (−0.30 to −0.02, $p=0.026$) and presence of PSE (0.16 to 1.73, $p=0.019$).

Conclusions Even after accounting for increased functional dependence, our study data indicates that caring in a PSE context may significantly increase carer strain, comparable to a six-point reduction on the Barthel Index.

Trial registration number NRS Stroke Research Network ID 18980.

BACKGROUND

Post-stroke emotionalism (PSE) is a widely acknowledged, clinically prevalent neurological stroke sequela characterised by frequent, sudden onset crying episodes (occasionally laughter), not under usual social control and which represent a change from pre-stroke functioning.^{1–3} At least one in five stroke survivors at 6 months suffer PSE^{4 5} yet compared with other common neurological stroke conditions, for example, neglect or aphasia, PSE remains under-researched.⁶ Emotionalism

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first analysis of carer strain associated with emotionalism following a stroke.
- ⇒ However, the data were derived using only one measure at one time point when the caregiver was present and willing to participate.
- ⇒ Research into larger cohorts of stroke survivors with emotionalism and their carers is needed.

is not stroke specific and can arise following a range of neurological diseases impacting brain areas and pathways functionally linked to emotion expression and regulation.⁷ In the stroke context, PSE is associated with younger age, cognitive impairment, larger lesions and strokes disrupting serotonergic and/or bulbar brain networks.^{5 7} PSE can be upsetting and confusing for patients and families, and potentially misunderstood for depression by clinicians because of the central crying component. There may be co-presentation with clinical depression, adding to the risk of misdiagnosis. Standardised assessments are available.^{8 9} If ignored or missed, PSE can disrupt stroke rehabilitation as patients disengage or avoid therapies for fear of crying, distress or embarrassment, in turn eroding functional and quality of life outcomes.¹⁰

Caregiver burden is a widely recognised phenomenon in the stroke context, prevalent in 25%–54% of cases, and associated with a range of stroke survivor characteristics, including more severe illness and behavioural changes due to mood and/or cognition impairments.^{11 12} Surprisingly, however, despite the prevalence and nature of PSE and its psychological associations established by quantitative and recent qualitative research,^{13–16} little is specifically known regarding the impact of caring for people living with PSE.

Colamonic and colleagues progressed an online survey which included carers of people with and without emotionalism following a range of precipitating neurological diseases, including stroke.¹⁰ Three self-report measures were completed by

the carers: the Center for Epidemiologic Studies Depression Scale 10-item (CESD-10),¹⁷ the Screen for Caregiver Burden (SCB)¹⁸ and the Work Productivity and Activity Impairment questionnaire (WPAI).^{19 20} Interestingly, those caring for people with emotionalism showed equivalent levels of depression to carers of people without emotionalism. Whereas among the emotionalism carers, there were more frequent burdensome events, higher distress levels, greater disruption to work productivity and work impairment, including missed time at work, and more caregiver burden overall.¹⁰

These are important data. They suggest increased carer burden and occupational dysfunction linked specifically to emotionalism, over and above the impact of caring in the context of the index neurological disease without concomitant emotionalism.

Notably, however, carers in the Colamonic survey were from a mixed neurological disease sample. Under one-sixth of the carer samples were stroke carers (n=59), and data specific to caring in the context of stroke emotionalism are not separately reported.¹⁰ Thus, the specific psychological impact of caring for people with emotionalism after a stroke is not known, and we could find no other studies which have explored this topic directly. This is an important gap. Stroke is distinct aetiological from other neurological diseases causing emotionalism (eg, multiple sclerosis, Parkinson's disease) and with separate clinical care pathways. It is thus crucial not only to understand the distinctive nature of emotionalism following stroke but also the distinct nature of carer strain linked to emotionalism following stroke.

Our primary aim was to address this knowledge gap, via an analysis of Modified Caregiver Strain Index (MCSI)²¹ data, collected from carers of individuals with or without diagnosed PSE 6 months post index stroke derived from the TEARS (Testing Emotionalism After Recent Stroke; NRS Stroke Research Network ID 18980) longitudinal cohort study.⁵

AIMS

As the TEARS data set contains MCSI scores from carers of individuals with stroke and PSE but also stroke and no PSE, the study had three aims:

1. To explore the degree of carer strain in carers of individuals with diagnosed PSE and to compare this to the degree of carer strain in carers of individuals with stroke but no diagnosis of PSE.
2. To examine whether carer strain varies with particular characteristics of the cared for individual: patient age, sex, social deprivation, stroke type, functional status and mood status (depression, anxiety).
3. To quantify the impact of PSE on carer strain, after accounting for other factors.

METHODS

Sample size

The TEARS cohort study recruited n=277 participants. Of these, n=102 had informants at 6-month follow-up who reported carer strain data. Of these, 66 were shown not to have PSE at 6 months, 16 to have PSE at 6 months and 20 not to have PSE status determined. To compare a normally distributed outcome measure between the 66 non-PSE and 16 PSE carers, there would be 81% power to detect a standardised measure of 0.8 and 94% power to detect a standardised measure of 1.0. These differences can be compared with the range of MCSI which is 0–26. Thus, there was sufficient power to detect clinical differences in the continuous outcome, provided that it was sufficiently close to normal in distribution.

Participants

Participants were recruited into TEARS from nine Scottish hospital acute stroke units within 2 weeks of sustaining stroke (<https://www.stroke.org.uk/research/understanding-difficulty-controlling-emotions-after-stroke>; full protocol available from NB) between 1 October 2015 and 30 September 2018. For each participant, an informant (spouse or closest relative) was recruited.

All stroke participants were male or non-pregnant female, ≥18 years of age, with a clinical diagnosis of first ever or repeat ischaemic or haemorrhagic stroke. We excluded on the basis of subarachnoid haemorrhage, other extra-axial bleeds, transient ischaemic attack, severe concurrent medical conditions, severe distressing behaviours precluding participation, aphasia (score <25 on Frenchay Aphasia Screening Test),²² life expectancy ≤3 months and/or lack of spoken English. Our clinical research file and site staff training required that the MCSI was completed for all patients 'by interviewing the nearest relative/carer'. Furthermore, the MCSI instructional set referred to the respondent as 'caregiver'. We did not gather data on informant respondent characteristics, other than confirming next of kin or equivalent to the stroke participant, nor the relationship between the participant and informant or whether the relative/carer interviewed was definitely the primary caregiver.

Measures and procedure

TEARS had a priori ethical approval from the Scotland A Research Ethics Committee (IRAS Reference 157483). All participants gave written informed consent, including those informant participants whose data are reported here.

Findings are based on data (all measures) gathered face-to-face at the 6-month assessment point by pre-trained stroke research nurses based on the stroke units.

Carer strain was determined using the MCSI.²¹ The scale was developed for use with family carers based on the original Caregiver Strain Index version.²³ MCSI is self-report and contains 13 items including prompting examples across a range of pertinent strain domains (physical, personal, psychological, financial, social) with item

responses captured as follows: 'Yes, on a regular basis' (scored 2), 'Yes, sometimes' (scored 1) or 'No' (scored 0). This gives a possible total score ranging from 0 (no carer strain) to 26 (highest carer strain).

MCSI has acceptable internal ($\alpha=0.90$) and test-retest reliability ($\alpha=0.86$) based on the Thornton and Travis sample²¹ and has been used previously to screen carer burden in the context of neurological disease,^{24 25} including stroke.²⁶

Diagnosis of PSE status was reached using Testing Emotionalism After Recent Stroke-Diagnostic Interview (TEARS-IV) 5. TEARS-IV is a detailed, semistructured diagnostic interview comprising three sections addressing post-stroke crying (screen questions, case characteristics, frequency and impact), post-stroke laughter (screen questions, case characteristics) and diagnostic summary. Final TEARS-IV diagnosis is reached based on published, widely accepted PSE diagnostic criteria^{1 13 14 27}: (1) increased tearfulness, (2) crying comes on suddenly, with no warning, (3) crying not under usual social control and (4) crying episodes occur at least once weekly.

We classified stroke using the Oxford Classification System²⁸ and used the Hospital Anxiety and Depression Scale (HADS)²⁹ to measure anxiety and depression, Barthel Activities of Daily Living Index³⁰ for functional outcome and computed social deprivation level using the Scottish Index of Multiple Deprivation rank provided by the Scottish Government. This is based on 6976 data zones. A rank of 1 corresponds to the most deprived area or data zone and 6976 the least deprived.³¹

Patient and public involvement

We originally targeted PSE for clinical observation research based on a national stroke research setting exercise involving Scottish stroke patients, carers and health professionals undertaken by James Lind Alliance.³² This identified 'What are the best ways to help people come to terms with the long-term consequences of stroke?' as the second top research priority. We did not involve patients in the design of the study, nor in the recruitment to, and conduct of, the study. The final TEARS-Q and TEARS-IV outcome measures were endorsed by a person with personal experience of stroke. Interested study participants could contact the study team to receive a summary of the study results posted to them.

Statistical analysis

All inferential analyses were conducted using R software V.4.2.3.³³ We deployed initial cross tabulation and follow-up statistics characterised the subsample from whom carer strain data were collected. Cross tabulation was used to explore the association of carer strain (MCSI) with stroke classification recorded at baseline and PSE status (yes/no on TEARS-IV), anxiety (HADS-A), depression (HADS-D) and Barthel Activities of Daily Living Index measured at 6-month follow-up when MCSI was also measured.

On initial inspection, the MCSI carer strain data had a skewed distribution. To improve variance stabilisation, we used the square root of MCSI, hereafter $\sqrt{\text{MCSI}}$, for modelling.

Univariate analyses were undertaken, regressing $\sqrt{\text{MCSI}}$ on each covariate separately to identify covariates with the strongest association with $\sqrt{\text{MCSI}}$. Then, a suitable regression model was fitted. In particular, we focused our interest on PSE which was considered to lead to greater anxiety and depression. Thus, the model for $\sqrt{\text{MCSI}}$ was regressed on PSE status and other covariates but not HADS-A nor HADS-D. The final model was selected to be a parsimonious fit for which all regression coefficients were statistically significant at the 5% level. We note that this is an exploratory approach and the parsimonious model fit avoids any nuisance variables.

RESULTS

Participants

Characteristics of the final sample are shown in [table 1](#).

As is evident, there were no significant differences between participants whose carers completed MCSI compared with those who did not, on variables of sex, age, social deprivation, anxiety, depression and stroke classification. There was MCSI variation by TEARS recruiting centre, likely reflective of differences in unit resourcing rather than participant differences. Furthermore, when PSE status was not recorded, MCSI data was also not recorded, largely explained by participants (and therefore carers) not attending for 6-month data collection.

As 175 participants did not return a measure of carer strain and only 102 did, we did not consider imputation methods for subsequent analyses. Instead, we continued noting that, based on participants' characteristics, there was little evidence of any association with the presence or absence of carer strain measurements, and thus, no selection bias was suspected.

Carer strain

Scores on MCSI range from 0 to 26 and were distributed as per online supplemental figure 1. As is evident, the distribution was heavily skewed. For better modelling, we therefore computed $\sqrt{\text{MCSI}}$, plotted in online supplemental figure 2. Prior to transformation, the MCSI distribution had a median of 4.0 and a mean of 6.0. Following transformation, the distribution had a median of 2.0 and mean of 2.0.

Association of MCSI total score with appropriate putative predictors

Next, we examined the association of participant sex, age, social deprivation, anxiety, depression, Barthel Index, stroke classification, carer strain and $\sqrt{\text{MCSI}}$ by PSE status at 6 months.

As is evident in [table 2](#), anxiety was higher in patients known to have PSE, but not statistically significant in this sample. The Barthel Index was lower in patients known

Table 1 Participant characteristics, cross-classified by collection of caregiver strain on MCSI

Variable	Levels	No MCSI data collected (%)	MCSI data collected (%)	P value
N of participants	Total	175	102	
Centre	A	51 (82.3)	11 (17.7)	<0.001
	B	5 (100)	0 (0)	
	C	20 (83.3)	4 (16.7)	
	D	51 (53.1)	45 (46.9)	
	E	9 (75.0)	3 (25.0)	
	F	2 (50.0)	2 (50.0)	
	G	15 (41.7)	21 (58.3)	
	H	11 (52.4)	10 (47.6)	
	I	11 (64.7)	6 (35.3)	
Sex (%)	Female	80 (65.6)	42 (34.4)	0.543
	Male	95 (61.3)	60 (38.7)	
Age at stroke	Mean (SD)	66.6 (14.8)	65.7 (14.1)	0.618
SIMD	Mean (SD)	2600 (2020)	2966 (2032)	0.152
Anxiety (HADS-A)	Mean (SD)	5.6 (4.5)	5.6 (4.8)	0.979
Depression (HADS-D)	Mean (SD)	4.4 (4.1)	4.6 (3.8)	0.772
Stroke classification	PACS	66 (65.3)	35 (34.7)	0.854
	LACS	51 (60.7)	33 (39.3)	
	POCS	39 (66.1)	20 (33.9)	
	TACS	12 (54.5)	10 (45.5)	
	Not recorded	7 (63.6)	4 (36.4)	
Emotionalism 6 months	PSE	16 (50.0)	16 (50.0)	<0.001
	No PSE	61 (48.0)	66 (52.0)	
	Not recorded	98 (83.1)	20 (16.9)	

HADS-A, Hospital Anxiety and Depression Scale, Anxiety subscale²⁹; HADS-D, Hospital Anxiety and Depression Scale, Depression subscale²⁹; LACS, Lacunar Stroke; PACS, Partial Anterior Circulation Stroke; POCS, Posterior Circulation Stroke; SIMD, Scottish Index of Multiple Deprivation³¹; TACS, Total Anterior Circulation Stroke.²⁸

to have PSE, suggesting that emotionalism associates with greater functional dependence. The sqrt.MCSI stabilised the variance (and therefore the SD), with carer strain higher for those with known PSE.

To establish the associations between carer strain and patient characteristics, sqrt.MCSI was therefore regressed on age, sex, deprivation (as measured by Scottish Index of Multiple Deprivation (SIMD) rank), Barthel Index, stroke class (Oxford classification measured at baseline) and PSE status at 6 months. Covariates that did not achieve statistical significance (by Wald test) were dropped to obtain a parsimonious final model. HADS anxiety and HADS depression were not included in this modelling since they were considered to arise from PSE and functional status (as measured by the Barthel Index).

The results of modelling are provided in [table 3](#) with univariable results included for reference, since these were used to suppress terms with little evidence of association to sqrt.MCSI (p values >0.1). As is evident, the final model had two covariates: Barthel Index and PSE status. These were the root sources of the associations within the

data. Participants with a lower Barthel had higher associated values of sqrt.MCSI (carer strain). The size of the effect was such that a six unit decrease in Barthel Index, say from 20 to 14, was associated with a unit (1.0) increase in sqrt.MCSI.

Moreover, PSE was associated with a 0.91 point increase in sqrt.MCSI. While it is difficult to practically assess patients on a sqrt.MCSI scale, the effect size of PSE on MCSI would be similar to a six point difference on the Barthel Index.

[Table 2](#) shows the unadjusted average carer strain of those with PSE to be 9.75 compared with an unadjusted average of 4.23 in those without PSE. Further modelling was undertaken to explore the nonlinear effects of social deprivation, age and Barthel Index. These are not reported since the effects were acceptable as linear.

Finally, we produced a violin plot with boxplot within to reflect more details of the distribution of carer strain ([figure 1](#)), including carer strain adjusted from the final model for the association with Barthel ([figure 2](#)). As is evident, the distribution of MCSI data among carers of

Table 2 Participant characteristics, cross-classified by PSE status at 6 months

	PSE	No PSE	Not recorded	P value
N of participants	16	66	20	
Sex=male (%)	10 (62.5)	37 (56.1)	13 (65.0)	0.736
Age at stroke (mean, SD)	56.75 (14.91)	66.05 (13.06)	71.55 (13.98)	0.006
SIMD (mean, SD)	2000.31 (1841.62)	3341.26 (2093.65)	2472.84 (1637.68)	0.029
Anxiety HADS-A (mean, SD)	7.33 (5.77)	5.46 (4.47)	3.62 (4.47)	0.183
Depression HADS-D (mean, SD)	4.40 (4.50)	4.64 (3.63)	4.62 (3.70)	0.975
Barthel ADL (mean, SD)	17.88 (3.69)	19.23 (1.58)	14.74 (6.05)	<0.001
Stroke classification (%)				0.069
PACS	4 (25.0)	23 (34.8)	8 (40.0)	
LACS	6 (37.5)	23 (34.8)	4 (20.0)	
POCS	4 (25.0)	14 (21.2)	2 (10.0)	
TACS	1 (6.2)	3 (4.5)	6 (30.0)	
Not recorded	1 (6.2)	3 (4.5)	0 (0.0)	
Carer strain MCSI	9.75 (8.52)	4.23 (4.89)	8.75 (6.48)	<0.001
sqrt.MCSI	2.73 (1.56)	1.61 (1.29)	2.60 (1.44)	0.001

Barthel ADL, Barthel Activities of Daily Living Index³⁰; HADS-A, Hospital Anxiety and Depression Scale, Anxiety subscale²⁹; HADS-D, Hospital Anxiety and Depression Scale, Depression subscale²⁹; LACS, Lacunar Stroke; MCSI, Modified Carer Strain Index; ²¹ PACS, Partial Anterior Circulation Stroke; POCS, Posterior Circulation Stroke; SIMD, Scottish Index of Multiple Deprivation³¹; TACS, Total Anterior Circulation Stroke²⁸.

people with PSE had a higher median, greater IQR with more frequent low scores, which held for the distribution adjusted for Barthel.

DISCUSSION

To the best of our knowledge, this is the first study to examine carer strain in the context of emotionalism after stroke. We deployed a widely used, validated measure of carer strain and compared the psychological impact of

caring for people with stroke and emotionalism to the impact of caring for people with stroke but no emotionalism. We also considered whether carer strain varied with the particular characteristics of the cared for individual, including age, sex, stroke type, deprivation, mood and functional status.

Several key findings emerged. First, we did not observe any significant association between carer strain measured on MCSI and sex, age, deprivation level or stroke type of

Table 3 Table of regression coefficients, with sqrt.MCSI as a dependent variable

		Coefficient (univariable)	Coefficient (multivariable)
Sex	Female	–	–
	Male	0.09 (–0.49 to 0.67, p=0.756)	–
Age at stroke		–0.00 (–0.03 to 0.02, p=0.630)	–
Social deprivation		–0.17 (–0.30 to –0.03, p=0.19)	–
Barthel ADL		–0.14 (–0.21 to –0.06, p<0.001)	–0.16 (–0.30 to –0.02, p=0.026)
Stroke Classification	PACS	–	–
	LACS	0.09 (–0.60 to 0.77, p=0.806)	–
	POCS	0.43 (–0.37 to 1.22, p=0.291)	–
	TACS	1.14 (0.12 to 2.16, p=0.029)	–
	Unknown	–0.13 (–1.63 to 1.37, p=0.868)	–
PSE status 6 months	No PSE	–	
	PSE	1.13 (0.38 to 1.87, p=0.004)	0.95 (0.16 to 1.73, p=0.019)

Barthel ADL, Barthel Activities of Daily Living Index³⁰.

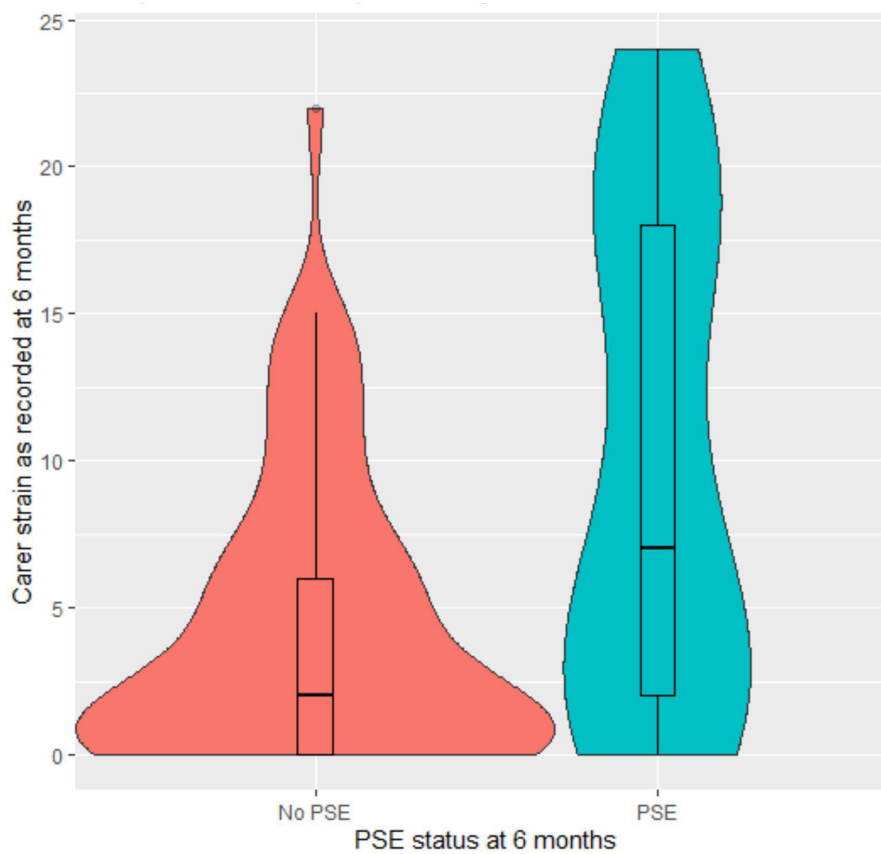


Figure 1 Violin plot with nested boxplot of unadjusted carer strain.

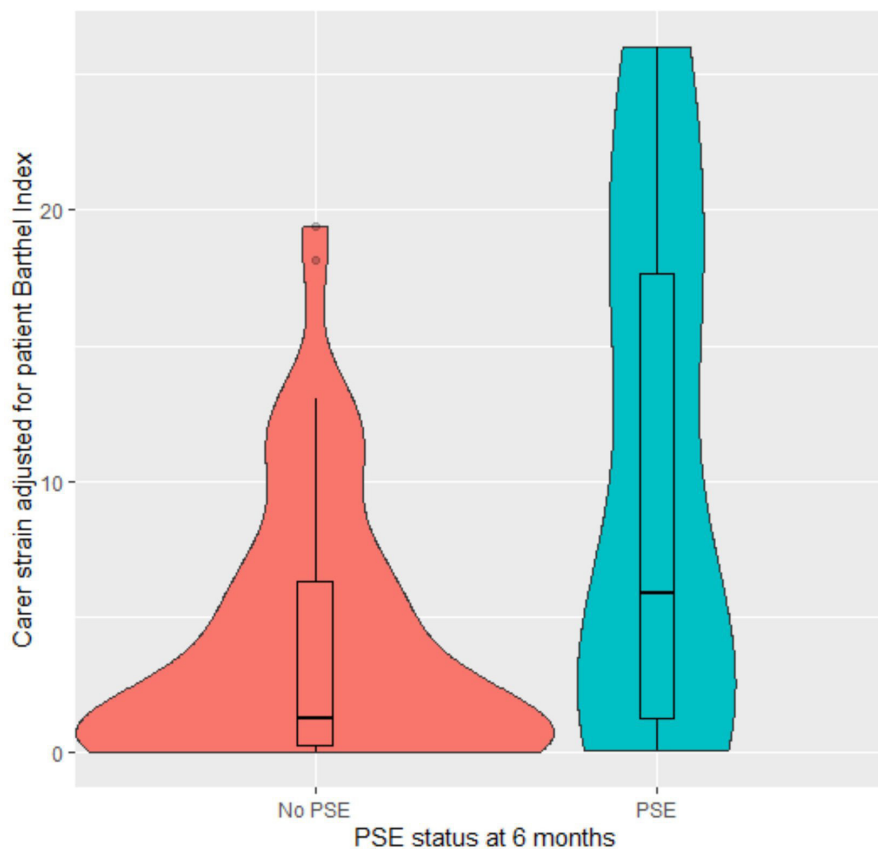


Figure 2 Violin plot with nested boxplot of adjusted carer strain.

the cared for individual. By contrast, we observed a clear and substantial association between carer strain and functional dependence on the Barthel Index. Specifically, greater functional dependence is associated with greater carer strain. Moreover, we also observed a significant association between carer strain and PSE status, strain being greater among carers of individuals with diagnosed PSE, compared with carers of individuals with stroke but no PSE. Consistent with these effects, when we regressed carer strain on age, sex, deprivation, Barthel Index, stroke type and PSE status at 6 months, the final model had two covariates: Barthel Index and PSE status. Again, higher carer strain was associated with greater functional dependence and diagnosed PSE.

Overall then, our analyses suggest a substantial association between functional dependence and carer strain but also between PSE status and carer strain, remaining after accounting for the impact of functional dependence measured by the Barthel Index. Consistent with the effects Calamonic and colleagues observed across the neurological disorders, our analyses indicate that caring in a PSE context significantly increases carer strain, equivalent to a six-point difference on the Barthel scale.

This is a unique study of carer strain in stroke patients assessing the impact of PSE on carers and the first to directly address this topic. We analysed MCSI data collected at 6 months post index event rather than acutely. Our assessments were conducted face to face with participants and their caregivers rather than online. Colamonic and colleagues took an online survey approach, using the self-report Centre for Neurologic Studies-Lability Scale⁹ to denote emotionalism status of the cared for individuals. By contrast, we diagnosed PSE status using a semistructured diagnostic interview, constructed based on House diagnostic criteria of PSE,¹ delivered face-to-face to people with stroke and their caregivers by stroke research nurses, pre-trained by the senior author, an emotionalism expert.

A number of study limitations must be highlighted. Although larger than the cohort of stroke caregivers surveyed by Colamonic, our sample size of 102 caregivers is still relatively small making the study underpowered with data obtained from an observational study. Moreover, only 82 were associated to stroke survivors with known PSE status and with MCSI data returned, and only 16 were carers of people with PSE. There are also likely to be some unmeasured differences between those who did, and those who did not, complete the follow-up MCSI survey. Replication will be required using a larger cohort of stroke survivors with PSE and their carers, although our sample is similarly modest to that of Colamonic and colleagues (59 stroke caregivers) who observed a similar effect.

The measurements were carried out as part of the follow-up of the TEARS cohort study and thus represent observational data. Furthermore, the data were only collected at a 6-month follow-up session whenever the

carer was present with the patient and willing to participate and we did not record carer characteristics or whether the relative/carer interviewed was the primary caregiver. We only examined respondent/non-respondent differences on certain key variables; and thus, although we observed no evidence of sampling bias, this could still have influenced the data. Our conclusions must also be limited as they may not apply to where the patients have more severe stroke (see table 1 for details). Consequently, they should be regarded as a convenience sample at one time point. Nonetheless, there is no suspicion of bias in the findings and participation of carers appeared to be representative of the observed characteristics of the patient population. Finally, while MCSI has acceptable psychometrics²¹ and previous use in stroke,²⁶ the scale lacks established cut points. While this makes it hard to determine the clinical extent of carer strain seen in our data, the unadjusted average carer strain of those with PSE is 9.75, compared with 4.23 in those without PSE. The additional impact of caring in the PSE-specific context is thus clearly evident.

Clinical implications

While from a preliminary observational study and only at one time point, the data have important clinical and research implications. Clinically, additional psychological strain might be expected to arise in carers of individuals with PSE, something stroke clinicians and rehabilitation teams should hold in mind when PSE is detected. Targeted screening of carers of those with emotionalism using MCSI and other reliable measures could form an additional element of stroke care. Strain among carers of those with chronic PSE might be expected to escalate beyond 6 months, although larger scale longitudinal research beyond 6 months will be required to determine this. Although there has been recent qualitative research exploring the lived experience of emotionalism,^{15 16} research using qualitative approaches is also needed to improve our understanding of the lived experience of caring for someone with PSE, including what can help both the patient and the carer, psychologically. This important research could in turn inform badly needed work to adapt current evidence-based psychological interventions aimed at reducing carer strain in the broader stroke context and then test these for the PSE context.

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Contributors NB, MW and RMW made substantial contributions to the conception and design of the work and the interpretation of the data. NB and MW led the acquisition of the data, and RMW led the analysis of the data. NB, MW and RMW drafted the work and reviewed it critically for important intellectual content and approved the final manuscript version for publication. NB, MW and RMW agreed to be accountable for all aspects of the work. NB is responsible for the overall content as guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and was approved by Scotland A Research Ethics Committee (IRAS Reference 157483). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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